



MAY 10, 2024

CDC's website is being modified to comply with President Trump's Executive Orders.

Living with ME/CFS

KEY POINTS

- Patients and their families need support as they come to understand how to live with ME/CFS.
- Healthcare providers and families should know that this process might be hard on people with ME/CFS.
- ME/CFS affects each person with the illness differently.



How it impacts everyday life

ME/CFS affects each person differently.

Mildly impaired people with ME/CFS may be able to keep working or going to school with careful planning and activity management. These strategies may also allow them to keep participating in social and family activities.

Moderately impaired people with ME/CFS may have trouble maintaining a regular work schedule. They may limit social and family activities in order to keep working.

Severely affected people with ME/CFS may be wheelchair-dependent and house- or bed-bound. This severity can last for months or even years. Patients who are bed-bound might need assistance performing daily tasks, such as bathing or cooking.

Everyday strategies

Healthcare providers can treat some symptoms with medicine, but there are other management strategies that do not involve medications. These strategies may be helpful to some patients:

- Professional counseling. Talking about how to cope with the illness and its impact on daily life may help.
- Occupational counseling to identify workplace accommodations and strategies to conserve energy while performing daily living activities.
- Balanced diet. This is important for everyone and benefits people with or without chronic illness.
- Nutritional supplements. Benefits and risks of interactions with other medications should be considered.
- Other therapies. Meditation, gentle massage, deep breathing, or relaxation therapy might help.

Important note: Patients should talk with their healthcare providers about all therapies before beginning them. Many treatments promoted as cures for ME/CFS are unproven, often costly, and could be dangerous.

Voice of the Patient

The Voice of the Patient series highlights people with ME/CFS in their own voices. These stories are from women and men, patients and caregivers, and people of different ages and racial and ethnic groups. We are honored they have chosen to share their stories with CDC and other readers.

Eleanor's story



Eleanor received a diagnosis of ME/CFS following COVID illness.

Eleanor

NOTE: Eleanor's story is one of ME/CFS following acute COVID-19.

My story starts off with a timeline of my symptoms. In July of 2021, I tested positive for COVID. I have been a nurse for 12 years and work at a busy hospital, but I probably got COVID the way many people have—through my son and his daycare provider. I never had a history of infection before getting COVID. My symptoms were fatigue, swollen lymph nodes, muscle and joint pain, fever, chills, and dizziness when standing and walking. Over the next week my fever resolved, and my muscle pain and lymph nodes improved. I had a cough and total loss of smell, taste.

By August I was back at work but was easily exhausted and short of breath. I took the elevator now when I previously took the stairs. In September, I started to experience difficulty concentrating and finding words, and I needed to write things down unlike before when I could multitask without effort. I could not drive without the GPS system even when a route was routine. I also experienced forgetfulness.

In October, I got a COVID booster shot and after, I felt like the dizziness was not as bad, but the fatigue was still there. At this point I had to change my work schedule. I had worked three 12-hour shifts but now had to make sure that I took a day off in between each shift so I could recover, especially from the feeling of being exhausted after doing something. And the brain fog and insomnia were hard. As I planned Thanksgiving, I almost went over the edge with depressing thoughts, and had difficulty making non-routine decisions or choices.

I made an appointment at a post-COVID clinic, but it took until January 2022 for me to see the doctor. The doctor told me that my post-COVID symptoms were parallel to ME/CFS and that it was all very similar. For me, the neurological symptoms (dizziness, brain fog), fatigue, and POTS (postural orthostatic tachycardia syndrome) were the worst. Also, the activity intolerance. Learning to live with my symptoms and the management plan (medications and building in breaks) have helped me.

My family is from Southeast Asia and the cultural traditions are different, but we maintain many of them through family celebrations and respecting our elders. In many Southeast Asian cultures if you have symptoms that are not physical, then your illness does not exist. Mental illness or depression and anxiety are taboo. My family had not heard of ME/CFS but commented that I cannot be tired forever.

My husband has been very supportive although he has struggled at times with being the primary caregiver for me and our son. For example, I would vacuum and then be flat out tired. Or I would cook and forget certain ingredients. Looking back, I wish I would have taken a longer leave time when I was first diagnosed with COVID because I was just not functional.

I was scared when the doctor told me ME/CFS because I knew a coworker who had it and I saw her decline. She said it was the most challenging period of her life. It really opened my eyes to ME/CFS, and I know now what it is like to have ME/CFS. I confess that my coworker did not just have anxiety or that it was all in her head; it was ME/CFS. My other coworkers and I should have paid more attention to this debilitating disease that has no lab test to pinpoint what is wrong. People who have it are suffering.

Katherine's story



Katherine, and her husband Ben, share their journey with ME/CFS.

Katherine

I was made aware of ME/CFS at an early age, seeing my mom, aunts, and grandmother all struggle to overcome it. It wasn't until college that I remember getting sick myself. From the time I was fourteen, I was waiting tables every weekend, maintaining straight A's and generally pushing

myself far past my limits. After a series of recurring viral infections and years of chronic strep throat, I had a tonsillectomy when I turned twenty-one. From this point on it felt like my body never fully recovered and looking back now, I can see how I had ignored all the warning signs.

My mom was a huge help to me in coping with my health decline, especially since I wasn't receiving support from medical professionals or full understanding from friends. Having someone close that understands how devastating and isolating this condition can be, makes all the difference in the world. I learned to manage alone as best as I could, and over the years even became a master at hiding my illness from the outside world.

I was able to maintain a very convincing outward appearance in all aspects of life: from the high achiever in school and at work; to the adventurous, and social butterfly at parties; and never letting anyone see fully behind the curtain. It was a constant cycle of publicly pushing and privately crashing. That is, until I met my husband, Ben.

We moved in together and married after only two years of knowing each other. I thought I had been lucky, in a sense, that his job required him to travel often, allowing me to secretly sleep for days. Then I would lie about what I had "accomplished" while he was away. Of course, as time went on, it became more and more difficult for me to hide what I was dealing with.

The anxiety and depression I developed over the years, and typically could keep at bay, was becoming overwhelming, as were my ME/CFS symptoms (non-restorative sleep, post-exertional malaise, muscle/joint weakness and pain, and brain fog). I was terrified of letting my husband see the real me, of being misunderstood as lazy or selfish, and ultimately of having my biggest fear of 'not being enough' confirmed.

Even though it was one of the hardest things to do, I shared everything with Ben, and it was the best thing that ever happened to me. He was wonderfully kind, and we created a plan to get my health (physical and mental) back in balance. I was officially diagnosed with ME/CFS shortly after I turned 30. It gave me the justification I didn't know I was looking for and helped me to start living more honestly with this illness.

Most importantly, I committed to therapy and have worked to let go of the shame I built up over the years. For the first time, I mourned the loss of the person I once was and am learning to have more compassion for who I am moving forward. With the additional help of antidepressants, I've realized I never would have taken control of my health in this way if I hadn't gotten sick. And though I continue to struggle daily, I remind myself that many things in my life are richer because of it – most notably my relationship with my husband and with myself, my outlook on the future, my empathy and compassion for others, and my reignited passion for art.

Although this illness continues to weigh heavily on my heart and body, having the knowledge I now have and knowing there's a growing community of support keeps me joyful and full of hope.

Ben

ME/CFS can be a challenge but has also brought my wife and I closer together. The biggest challenge for me was understanding what "it" is. As an active person, it was tough for me to comprehend that chronic fatigue syndrome was more than just being "tired." It is a condition that requires planning and thought to ensure you are supporting your partner. ME/CFS is a condition that is tough to understand if you do not suffer from it, so the more awareness that can be brought to it the better understood it will be.

I have traditionally traveled often to see friends and family and haven't thought about "recovery days" or taking better flight times to be home at a reasonable time. For me, it was the "more the better." But what I've learned is that there needs to be a balance to enjoy travel. Understanding that you may need to have breaks during a trip, to rest or cut a trip short to accommodate a recovery day. Although these are small changes to a trip, this is one example of how to manage healthy relationships with your spouse that suffers from ME/CFS.

As with most relationships, communication is key. The more you can understand about what he/she is going through the more you'll be able to support them and understand what is needed. Knowing how and what you can do to support your spouse as they are struggling will be crucial to helping them through rough times and for you to not get frustrated. ME/CFS is a condition that can be "hid" from most friends, but once you are in a relationship living together, it will be exposed. At first, your partner may be embarrassed of the condition, but it's important to assure your spouse that you will support them as you work together to find a balance for your relationship.

Disclaimer

The opinions and conclusions on this web page are those of the patients and other contributors, and do not necessarily represent the official position of the Centers for Disease Control and Prevention (CDC). The names of some contributors have been changed to protect their privacy.

Resources

CDC developed a [ME/CFS Patient Toolkit](#). It provides information about ME/CFS and helpful support for visiting a healthcare provider.

Archived Voice of the Patient stories

[Adhira and Neel's Story](#)

[Andrew's Story](#)

[Liz's Story](#)

[Marlene's Story](#)[Ann's Story](#)[Max's Story](#)

SOURCES**CONTENT SOURCE:**

National Center for Emerging and Zoonotic Infectious Diseases (NCEZID)